Introduction

Death and dying in today’s managed care society are messy. I do not mean messy physically (although that may be the case as well), but messy emotionally and philosophically. This is particularly true when considering issues such as physician-assisted suicide and euthanasia. It is impossible to engage in the debates on these twinned issues without feeling that any answer reached will not be completely satisfactory. If it is decided that these practices should be allowed or at least decriminalised, then you have to accept the very real possibility that abuses may exist. If you take the contrary position – that these practices should not be allowed – then you have to deal with the fact that medical care at the end of life is often a painful, debilitating, dehumanising experience, despite the wonderful advances in palliative care and the care provided by medical staff.

I am not convinced, however, that this messiness is necessarily a bad thing. This should not be an easy issue. We are dealing with lives, both in a biological and in a narrative sense, which may be in conflict. We are dealing with fundamental philosophical ideas such as autonomy, choice, respect, dignity, paternalism, personhood and life, which may often pull in different directions. We are dealing with complex arguments that span philosophy, ethics, law and medical practice. Finally, we are dealing with empirical arguments when the information is not always readily available or easily analysable. These are basic human questions that do not readily lend themselves to easy answers. Nor should they.

In addition, of course, there is a plethora of academic (and non-academic) work in the area, much of it taking a specific perspective on, or focusing on a particular aspect within, the debates around the end of life.¹ Even if it were desirable to read everything that has been

¹ While the literature on the subject is too vast to list all of the possible academic sources on the subject, some of the most important books in the area are: R. Dworkin, Life’s...
Introduction

written about the subject, which is doubtful, to do so would be practically impossible. You may be required to look at materials from a particular jurisdiction only; alternatively, you may be limited to materials from a certain perspective (e.g. either legal, ethical or medical). You may simply read as widely as possible and hope for the best – i.e. to have read sufficient material to be able to provide a good general assessment of the issues, even at the risk of ending up staring blankly at someone who has quoted the latest obscure text about some aspect of the end-of-life debate.

If it is already impossible to read everything within this morass of information, argument and opinion, what can one more work in the area possibly add? One answer is that it can attempt to be comprehensive. In other words, it can attempt to make it easier for those seeking to learn about the topic to be able to navigate the large collection of material and inform themselves about the debates on the end of life. There are two ways it is possible to accomplish this goal. First, one way that a book can be comprehensive is to look at the issues surrounding end-of-life treatment from more than one perspective.

Second, there is a tendency to focus on only one aspect of end-of-life decisions. Some academic works will focus, for example, on euthanasia and assisted suicide; others on particular aspects of one subject. For example, Keown, *Euthanasia, Ethics and Public Policy* and Lewis, *Assisted Dying and Legal Change*, both focus on euthanasia and assisted suicide generally. Griffiths *et al.*, *Euthanasia and Law in the Netherlands*, focuses on assisted dying practices in the Netherlands. Magnusson, *Angels of Death*, focuses on a particular empirical study that he performed.
1 Introduction

may interact is if one particular action is removed from the list of possibilities for legal reasons, then it may become more difficult for the doctor or health-care worker to act in what he or she might consider to be the most appropriate manner. The doctor may then feel that another option must be shoe-horned to fit what is believed to be most appropriate. Treatment options may then begin to resemble other options even if they did not do so originally. This may cause conflicts legally or ethically when trying to differentiate between certain practices, making it harder for health-care practitioners, lawyers and ordinary members of the community to decide which actions are acceptable and which ones are not. There is, thus, an important reason to consider these types of treatment decisions as a range of possibilities instead of isolated practices. It provides us with a greater consistency among practices, helps us to understand the relations between various practices and allows us to measure the impact one treatment has on other treatment possibilities.

Comprehensiveness is important, but it is not the only (or even the main) goal of this book. It is also my intention here to examine end-of-life issues in a way that reveals and illuminates the role of bioethics in modern life. Bioethics, like any form of ethics, is a philosophical pursuit designed to examine issues so as to allow us to live more moral lives. Its goal, then, is to make our lives better by providing a framework for making better (more moral) decisions. Indeed, some of the decisions bioethics is particularly concerned with can be some of the most difficult decisions we could ever face, and we might expect that advice and input from people more accustomed to thinking through the various dilemmas and complexities involved in such decisions may often be very welcome. But that is not always the case with bioethics.

Disability rights groups protest against bioethicists either in person or online. Peter Singer, one of the world’s most famous bioethicists, is all but barred from speaking in Germany. The Catholic Church has even recently suggested that some of the most dangerous types of ‘new sins’ occur in bioethics. Not medical science, biology or science in general—but bioethics.

As a result, we have a field of study that is supposed to improve our moral lives which has been characterised as a malign influence. We have

---

3 See, for example, the website of the disability rights group, Not Dead Yet, http://notdeadyetnewscommentary.blogspot.com/search/label/bioethics (accessed 21 June 2011) or P. Singer, Practical Ethics (2nd edn) (Cambridge University Press, 1993), pp. 337–359, where he discusses protests against him.

4 Singer, Practical Ethics.

Introduction

a field of study designed to help determine what is morally right which is often criticised for getting it so morally wrong. How then to explain this disconnect? In some ways, of course, this is not the fault of bioethicists or bioethics. Statements made by bioethicists can often be misinterpreted, misquoted or misunderstood. Quotations may be attributed to bioethicists which might be incomplete expressions of what they said. They may even be statements which are not representative at all of what the specific bioethicist has said. Peter Singer, in particular, seems to be routinely criticised for positions he either does not actually hold or to positions which are, at best, caricatures of his actual position.6

That this occurs so often should not necessarily surprise us. Bioethicists, like all philosophers, may care more about things such as the logical foundations of arguments or consistency of ethical positions than the ordinary member of the moral community.7 For bioethicists, it is less a concern of being able to live with the consequences of a decision than being able to defend that position in a published work – largely because bioethicists may not be confronting these issues directly (or at least not directly when they are writing the journal article or book). Ordinary members of the moral community, who are likely to face these decisions only when they have a direct impact on their lives, are much more likely to be concerned about being able to sleep at night or look loved ones in the eye after making a decision than they are about the logical consistency or reasonable defensibility of that decision. So, the risk of making a decision which is contrary (or apparently contrary) to another, earlier decision probably matters less to an ordinary member of the moral community than to a bioethicist.

An acceptance that these are two separate projects – resolving ethical dilemmas in our own lives, and engaging in academic debate about ethics – does not mean that the dichotomy goes away. While some blame belongs to those who misrepresent, intentionally or otherwise, the positions or aims of bioethics, there is also fault on the part of bioethicists themselves. That is because bioethicists do sometimes say some rather counter-intuitive things. Some bioethicists claim that apes are entitled

---

6 Peter Singer’s responses to most of the common misunderstandings of his theory can be found at his website: www.princeton.edu/~psinger/faq.html (accessed 21 June 2011).

7 I am going to use the phrase ‘ordinary member of the moral community’ throughout this book as a shorthand for those individuals who would not consider themselves or be considered by others to be an expert on bioethics. So, essentially, someone who does not spend their professional life researching issues of medical law and ethics. Another possible term for this might be the oft-quoted UK legal phrase of the ‘man on the Clapham omnibus’. For reasons that will become apparent in the chapter on moral status, I will avoid that particular phrase.
1 Introduction

to more moral status than human infants, especially, but not exclusively, those which could be classified as severely disabled.⁸ We may make the same sorts of claims about those with dementia, or in persistent vegetative states.⁹ Alternatively, we may claim that even patients who have no chance of recovery or improvement should be continued to be maintained by medical science, despite what doctors advise or what the family of the patient or indeed anyone else actually connected with the patient wants.¹⁰ We might argue that all life should be protected and therefore we are committing mass murder when we brush our teeth.¹¹ Add to this a plethora of terms that appear familiar but are used in highly technical and often confusing ways (for example, ‘personhood’, ‘quality of life’, ‘autonomy’, ‘dignity’, ‘harm’ and even – as we will see in Chapter 3 – ‘innocent’) and the whole thing can be impossible to work through.

What we seem to have, then, is a similar problem to the one in legal theory exposed by H. L. A. Hart in the first few pages of The Concept of Law.¹² We have an ever decreasing circle of people called ‘bioethicists’ who talk among themselves about ideas which are not only confusing to ordinary members of the moral community, but are seen as wrong, absurd or clearly wrong-headed. Even more importantly, we seem to have a situation where the ordinary member of the moral community appears to be unable to use these particular ethical frameworks. Nowhere is this starker than in the case of Peter Singer. Singer has long championed the idea that those who are not persons¹³ are not entitled to full moral consideration, particularly in relation to whether or not

---

⁹ J. Harris, ‘The Philosophical Case against the Philosophical Case against Euthanasia’, in Keown (ed.), Euthanasia Examined, pp. 36–49.
¹⁰ J. Keown, ‘Restoring Moral and Intellectual Shape to the Law after Bland’ (1997) 113 LQR 482–503. J. Finnis, ‘Bland: Crossing the Rubicon’ (1993) 109 LQR 329–337. In both cases, the argument presented is more complex than the one listed above. Both Keown and Finnis argue that intentional killing of a patient because the life of the patient is determined to be ‘worthless’ is unacceptable, but that some withdrawal of treatment in cases where it is futile is acceptable. However, it is clear that in the case in question, Airedale NHS Trust v. Bland [1993] 1 All ER 821, the doctors and family did intend to kill Anthony Bland and did so precisely because they saw the value of his continued existence as being ‘worthless’.
¹³ A term discussed in greater detail in Chapter 2.
they can be killed.\textsuperscript{14} Those who are not persons include patients with dementia. When his own mother was struck with dementia as a result of Alzheimer’s disease, Singer admits that he did not treat his mother in the way which his theory recommends.\textsuperscript{15} But, if Singer cannot abide by his own theory, why should the rest of us (who have no investment in the theory) be guided by it either if faced with similar circumstances?

The critical concept in bioethics, then, may be about usefulness. Despite its logical cohesiveness or internal consistency, a theory about ethics which is completely impractical may be of no more use than one based upon the teachings of the flying spaghetti monster.\textsuperscript{16} What is useful, however, is a theory of ethics that ordinary members of the moral community can put into practice. It is important to remember that ethics is, by and large, a personal thing. What matters is that the ethical system one adopts has to be a useful one for the individual. If an individual cannot see how an ethical system can be put into practice, they are likely to deride it as useless and ignore it. When evaluating an ethical system, then, perhaps we ought not to be focusing on whether it is a universally acceptable system, or one characterised by logical consistency or internal coherence. Rather, perhaps we should, when we evaluate the merits of an ethical system, place more emphasis on how readily it might be used by individuals in real-life situations. This is not to suggest that things like internal coherence and logical consistency are unimportant. It is very important that ethical systems be able to produce consistent results across a number of situations and display internal coherence. Otherwise, moral decisions may well be made on whims or random chance. Nevertheless, if you cannot put a theory into practice, all of its logical consistency and internal coherence count for nothing.

Chapters 2 and 3 of this book provide examples of what this means in practice. Chapter 2 concerns ideas about moral status and about how we determine who matters morally and who does not. This debate has long been dominated by two theories as to how we make these sorts of determinations. One theory holds that species membership is of primary importance. Human beings, quite obviously, are at the top of the chain and therefore are deserving of full moral status. Other species are entitled to less moral status and as such we may do things to them

\textsuperscript{14} Singer, \textit{Practical Ethics}, pp. 89–95.
\textsuperscript{16} For those interested, the flying spaghetti monster is a deliberately absurd creation intended to make a point about the difference between scientific evidence and religious belief. For further information about the flying spaghetti monster, see www.venganza.org (accessed 21 June 2011).
1 Introduction

which we may not do to human beings. The problem with this is that it is incredibly difficult to be able to show why human beings are entitled to this special status without relying on theological or self-serving arguments. But the alternative creates its own problems. The alternative to regarding species membership as the primary determinant for moral status is to focus on an entity’s possession of specific characteristics. These can be anything, but are most often things like rationality or sentience. However, this can mean that not all human beings are entitled to full moral status. Adopting a more easily satisfied characteristic (life, for example) only seems to create further problems; we may end up regarding bacteria as being as morally relevant as human beings, for instance. Consequently, we end up spending time debating these two different approaches while ordinary members of the moral community remain as confused as before or conclude that the whole debate is nothing more than some sort of elaborate joke.

Chapter 3 deals with the concept of the value of life and presents similar problems. Again, the debate in bioethics revolves around two positions. The first, referred to as the sanctity or inviolability of life, argues that life has an inherent value. The alternative position, known as the quality of life position, holds that life does not have an inherent value but is only valuable because of the things that it allows us to do. These two positions are said to be mutually exclusive – in other words, it is necessary to choose between them. Many ordinary members of the moral community, however, seem to prefer a compromise position between the two. They may want to insist, for some purposes, that life is inviolable, but to treat quality of life as being relevant at other times. Bioethicists, however, indicate that such selectivity is not possible without logical inconsistency.

Under the traditional bioethics formulations above, such issues may seem irresolvable. But the traditional formulations are not the only ones. This book will show that a different way is possible by providing, in Part I, a practical ethical formulation for end-of-life concerns. In order to do so, it will be necessary to return to the first principles involved in these particular issues. In other words, we have to start at the beginning in terms of the basic ethical and legal concepts and the broad frameworks they inhabit. In the cases of some of the ethical concepts, this will mean a re-examination of key ideas and a clearing out of some of the intellectual clutter that has arisen. What will remain, however, will be ethical concepts which are more readily available to and applicable by ordinary members of the moral community. These will then be worked together into an overall ethical framework from which we can make decisions about end-of-life treatment in a way which is
Introduction

intellectually coherent but still capable of providing practical moral guidance that it is actually possible to follow in our daily lives. This does not mean that the resulting ethical framework created in Part I will be universally acceptable. Not everyone who reads the framework will find it convincing or right. I make no claims, therefore, that the answers suggested here are the only valid ones. Instead, I aim only to suggest a useable, coherent framework which, I believe, offers a helpful way of negotiating the complexities of decision-making at the end of life.

But ethics is only part of the story when considering end-of-life treatment. It is also essential to ask whether and how the ethical framework created in Part I can be implemented by legal regulation. It is not a simple matter of merely taking the ethical conclusion and making that decision legally acceptable. Ethics is primarily about ideals – what we think that people ought to do, ideally, in certain circumstances. Often, the law cannot insist on ideals, but can only deal with the reality of particular situations. That means that even if we consider a decision to be ethically acceptable, problems in regulating behaviour may mean that the practice must be legally sanctioned. Concerns such as the impact on others unrelated to the action, the prevention of abuses, so-called ‘slippery slope’ arguments and procedural safeguards may all be stronger considerations in legal frameworks than in ethical ones. It is therefore necessary to consider to what extent the ethical answers arrived at in Part I of the book can be implemented in any legal framework and what type of legal framework is best suited to address not only the ethical questions but practical and legal questions as well. This will involve an examination not only of the legal structures available, but also of the empirical evidence that is available about these practices.

Part II of the book will therefore focus on the legal regulation of end-of-life decisions. As with Part I, there is considerable clutter that should be addressed. First, as with the ethical approaches, there is a tendency to regulate individual aspects of end-of-life decision-making in isolation, without regard to their interaction with other issues. So, for example, attempts may be made to legalise physician-assisted suicide or voluntary euthanasia or to change the manner in which we make withdrawal of treatment decisions for incompetent patients without wider discussion about the overall regulation of death and dying. Considering the interrelation between these various end-of-life issues, this is a significant oversight and one this book will seek to address. As such, the sections in Part II will not just focus on isolated aspects of end-of-life decisions, but rather will consider how the conclusions reached about the regulation of one practice will impact upon the regulation of other
1 Introduction

practices at the end of life. It will be possible at the end of Part II, therefore, to envisage a coherent regulatory scheme for all end-of-life decision-making, not just one or two practices.

In addition to the creation of a comprehensive regulation scheme, another focus of Part II of the book will be on clarification about how we should best evaluate the effectiveness of any such scheme. There are two points which are vital to any evaluation. The first thing to keep in mind is the appropriate standard for evaluation. For example, in many cases where people are examining whether to legalise assisted suicide or euthanasia they look at the possibility of breaking the law. Since the number of incidents where the law is broken is clearly not zero, they determine that assisted suicide and euthanasia should not be legalised. But looking for a rate of zero is extremely unhelpful in evaluating whether these practices should be legalised. No statute or legal rule is ever completely effective. Even if we consider the most trivial regulation (say a parking regulation) and couple it with the harshest penalty, we are unlikely to get complete success, presuming that success is compliance with the law. Why then should we expect this to be any different? One argument may be that we are dealing with human lives and therefore the stakes are much higher than in parking regulations or other trivial matters. This is, of course, true. That just means we ought to make sure that we get it right. To do so, we have to make the success rate as close to 100 per cent as we can. We should also try to create a law that is as foolproof as possible and therefore strive for complete success as an ideal. Even with all that, though, we need to keep in mind that despite our best efforts, we will not reach that ideal. So, basing decisions about regulation schemes for end-of-life decisions on whether they reach that ideal is fruitless.

Often, such unrealistic expectations of our regulatory schemes are accompanied by the failure to notice that all jurisdictions currently have a regulatory scheme in relation to end-of-life practices, whether they be statutory-based or based in the common law. The evaluation of any proposed new regulation must therefore include an appraisal of how the existing regulation works. When comparing regulatory schemes, we need to keep in mind the question of metrics. If our biggest concern is the rate of compliance with the law, it does no good to expect the new regulation to achieve a 100 per cent success rate if we are not expecting the same of the current regulation. In other words, we must compare like with like. Otherwise, we risk determining that the current regulation is the most appropriate despite it having a much lower success rate than an alternative.
Introduction

Considerations about the slippery slope argument\(^\text{17}\) present an example of unrealistic expectations coupled with a failure to recognise the existence of a current regulatory scheme. When evaluating regulations which would legalise or decriminalise voluntary euthanasia or assisted suicide, much is made of the possibility of a slide towards non-voluntary or involuntary euthanasia.\(^\text{18}\) In order to show this, commentators often rely on the evidence from the Netherlands which shows that there are instances of non-voluntary/involuntary euthanasia following the legalisation of voluntary euthanasia.\(^\text{19}\) This does not prove the point as convincingly as some commentators wish, however. All the Netherlands information proves (at least in isolation) is that the Dutch have not been completely successful in preventing non-voluntary and involuntary euthanasia. In other words, the Dutch system, like every other regulatory system including our own, does not command perfect obedience. As stated already, perfect obedience is an illusory goal anyway, and the lack of it should not be taken as evidence of any fundamental unsuitability of the regulation (or scheme of regulation) in question. Instead, these considerations only serve to underline the need to make comparisons on an equal footing in order that realistic assessments about the value of the various regulatory schemes available can be valid ones.

In summary, then, Part I will provide an examination of the ethical concepts which are relevant in decision-making about medical treatment at the end of life. The purpose of this part of the book is not only to present the current arguments about these ethical concerns but to critically analyse whether they actually provide a useful method for determining how we ought to act. From this, it will be possible to create an ethical framework at the end of Part I which will be able to provide one method for determining how we ought to treat patients at the end of life. Part II will take the conclusions reached in Part I and explore how best to legally regulate end-of-life decisions consistent with those conclusions, taking account not only of proposals for change, but also the currently regulatory system. From this, it will be possible to draw general conclusions about the ethical and the legal frameworks we should adopt to help us determine the acceptability of treatment at the end of life.

\(^{17}\) Slippery slope arguments will be explained in greater detail in Chapter 13.

\(^{18}\) See, e.g., Keown, *Euthanasia, Ethics and Public Policy*.

\(^{19}\) *Ibid.*